

Thursday, April 10, 2008

UT Southwestern Medical Center at Dallas
T. Boone Biomedical Building
Dallas, Texas

Facilitator: Donna Williams

MEETING NOTES

ATTENDEES:

<i>Sandra Billings</i>	√
<i>George R. Buchanan</i>	
<i>Donna Claey's</i>	√
<i>Robert Crumb</i>	
<i>Margaret Drummond-Borg</i>	√
<i>Alice Gong</i>	√
<i>Jose L. Gonzalez</i>	
<i>Charleta Guillory</i>	√
<i>Cheryl Hermerath</i>	
<i>Scott D. McLean</i>	
<i>Francisco Ramirez</i>	
<i>John Saito</i>	√
<i>Stuart K. Shapira</i>	√
<i>Eileen Sheridan-Shayeb</i>	
<i>Reid Sutton</i>	
<i>Larry Sweetman</i>	
<i>Lois Taylor</i>	

<i>Brad Therrell</i>	
<i>Sister Mary Nicholas Vincelli</i>	
<i>Morgan Walthall</i>	√
<i>Don P. Wilson</i>	
<i>Jerald L. Zarin</i>	√
<i>Margaret Bruch</i>	√
<i>Sherry Clay</i>	√
<i>Mirsa Douglass</i>	√
<i>Eldridge Hutcheson</i>	√
<i>David R. Martinez</i>	√
<i>Jann Melton-Kissel</i>	
<i>Susan Neill</i>	
<i>Sharon Newcomb-Kase</i>	√
<i>Susan Tanksley</i>	√
<i>Donna Williams</i>	√
<i>Susan Snyder</i>	
<i>Colleen Buechner for NNSGRC</i>	√

GOALS FOR MEETING

After opening statements and introductions, Donna Williams reviewed the agenda and goals for the meeting.

NEWBORN SCREENING FY 2008 BUDGET

Margaret Bruch presented Fiscal Year 2008 Budget for the newborn screening program for the laboratory and case management areas.

- NBS Laboratory budget comparison between FY 2005 & FY 2008
 - FY 2005 Budget, \$14 Million, based on 750K screens
 - FY 2008, \$21 Million, based on 816K projected screens
- NBS Case Management budget comparison between FY 2005 & FY 2008
 - FY 2005 Budget, \$0.7M, based on 12,065 cases to follow-up
 - FY 2008, \$4M, based on 16,700 projected cases to follow-up

Following presentation, discussions points were made:

- The NBS Open Enrollment Program was launched in 2007 offering funding for medication, treatments, services, food/formula etc. for families not eligible for Medicaid or CHIP. The program is currently enrolling subspecialists who would share the information with families; however, only 2 specialists have enrolled. The group brainstormed methods to get the message to physicians and families.
 - Participants wanted to know where specialists are located. It was suggested to add a link on the TNSP website that lists them. It was also suggested to provide information to TPA for their website and newsletter.
 - It was noted that the cost of low protein foods are not covered by insurance or Newborn Screening Open Enrollment.
- Steps taken to acquire additional staff for expansion included looking internally at open vacancies substantiating the need for positions to support newborn screening rather than their previous allocated assignments. Commissioner Hawkins directed an additional two employee positions be reassigned to family health.
- The Texas Health Steps (THSteps) Online Provider Education Module for NBS has been a success. Approximately 3000 CEU credits have been earned. Nurses hold the highest number earned followed by social workers, and physicians.
- Functions of two new case management educators were clarified. Their roles include visiting all birthing facilities to discuss expansion and specimen submission practices, attending meetings of professional associations/organizations, and onsite guidance to utilizing the new online provider training modules for NBS.

NEWBORN SCREENING PROCESSES

Susan Tanksley and David Martinez presented newborn screening laboratory and case management processes.

- Laboratory issues discussed included new process which automatically links 70 percent of 1st and 2nd screens (additional manual linking increased overall links to ~78percent); a large decrease in specimen rejections since adding a procedure to call for missing information on date of collection; and the designation of specimens collected at 7 days of age or later as follow-up specimens even if it's the child's first screen (necessary due to age related cut-offs).
- Case Management short term and long-term data management was discussed. The current laboratory information management system (LIMS) captures short term data, and long term data has also been captured for years. There is no data management system for the long-term follow-up (LTFU) data so the records are currently kept manually. The program is in the process of requesting a LTFU system, and the team provided suggestions including: considering having the disorders mandated as reportable disorders by CDC, using the Cystic Fibrosis case registry or other society registries as a model, or considering requests for federal funding for developing a registry since it's supported by the NBS Saves Lives bill soon to be approved.
- Participants wanted to know how many cases remain open and for how long when families cannot be found. Typically, they will remain open until the infant is located and appropriate action is taken with the infant. Concerns with keeping cases open included resources needed for ongoing tracking, and the potential of skewing program data.

MEETING PLUS/DELTA (FEEDBACK)

Participants shared thoughts about what they liked and didn't like about the meeting.

CHANGES

Nothing noted.

POSITIVE FEEDBACK

Appreciated sharing laboratory processing given on Thursday

Considered this meeting very informative

Great discussions

Great facility and location, Close to airport and hotel.

Speakers extremely prepared

Good ideas for further discussion

Comfortable exchange of information

Nice selection of room and location